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EDITORIAL

Designing AAC Research and Intervention to Improve Outcomes for Individuals with Complex Communication Needs

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Abstract
There is a rapidly growing body of research that demonstrates the positive effects of augmentative and alternative communication (AAC) intervention on the communication of children and adults with complex communication needs. Despite the positive impact of many AAC interventions, however, many individuals with complex communication needs continue to experience serious challenges participating in educational, vocational, healthcare, and community environments. In this paper, we apply the framework proposed by the International Classification of Functioning, Disability and Health (ICF) to illustrate the need to re-think AAC intervention to improve outcomes for individuals with complex communication needs, and to foster a new generation of intervention research that will provide a solid foundation for improved services. Specifically, the paper emphasizes the need to take a more holistic view of communication intervention and highlights the following key principles to guide AAC intervention and research: (a) build on the individual's strengths and focus on the integration of skills to maximize communication, (b) focus on the individual's participation in real-world contexts, (c) address psychosocial factors as well as skills, and (d) attend to extrinsic environmental factors as well as intrinsic factors related to the individual who requires AAC.

Keywords: *AAC; Autism; Cerebral palsy; Aphasia; Amyotrophic lateral sclerosis; Intellectual disability; ICF; Intervention; Outcomes; Research*

Introduction

I want her to be happy. I want her to love and to be loved. I want her to be safe and secure. I want her to be accepted for who she is. I want her to dream big and know the thrill and the satisfaction of accomplishments that come from hard work. I want her to have the courage to try and sometimes fail. At the end of the day, I want her to know that she left the world a little bit better than when she started out. (A parent talking about her goals for her child, a preschooler who uses AAC)

Listening to this parent talk about her goals for her child at an annual review and planning meeting precipitated one of those "aha moments" that provide a sudden jolt to see things in a new way. In the United States, as in many countries, these types of meetings are mandated by law (e.g., Individual Family Service Plan meetings for young children with disabilities; Individual Education Plan meetings for school-aged children with disabilities;

Individual Transition Plan meetings for adolescents and young adults) and are typically attended by a range of professionals from different disciplines (e.g., speech-language pathologists, occupational therapists, physical therapists, special educators, vision specialists, etc.) as well as family members. Typically, the meeting is filled with the presentation of assessment results and progress reports (Rummel-Hudson, 2008; Zeitlin & Curcic, 2014), and each professional discusses his or her goals for the child: For example, the physical therapist is working on improving weight bearing; the occupational therapist is working on fine motor skills and dressing; the special educator is working on early preschool concepts (e.g., numbers, colors, shapes); and the speech-language pathologist is working on increasing the range of speech sounds and using signs and picture symbols to make requests. But no one in these meetings ever talks about happiness; no one talks about developing and maintaining loving relationships; no one talks about acceptance; no one talks about dreaming big; no one talks about

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contributing to the world in a positive way. Rather, each professional focuses on his or her own disciplinary domain, with the underlying assumption that by targeting specific motor, cognitive, speech, and language skills, the interventions will effect positive outcomes overall.

At this team meeting, the parent of this preschooler questioned this basic underlying assumption. She articulated the goals that most parents have for their children, but her words illustrated the significant gap between current augmentative and alternative communication (AAC) research and services, and the long-term outcomes that individuals with complex communication needs and their families desire.

Outcomes for Individuals with Complex Communication Needs

Positive Effects of AAC

There is no question that there has been dramatic progress in the AAC field over the past 30 years. There is a rapidly growing body of intervention research that demonstrates the positive effects of AAC on the communication skills of individuals with complex communication needs, including, but not limited to, young children with complex communication needs (e.g., Branson & Demchak, 2009; Romski et al., 2010; Romski, Sevcik, Barton-Hulsey, & Whitmore, in press), as well as individuals with autism spectrum disorders (e.g., Ganz, in press; Ganz et al., 2011; Schlosser, in press); with severe or profound intellectual developmental disabilities (e.g., Mirenda, 2014; Roche, Sigafoos, Lancioni, O'Reilly, & Green, 2015; Snell et al., 2010); with challenging behaviors (e.g., Walker & Snell, 2013); with severe chronic aphasia (e.g., Beukelman, Hux, Dietz, McKelvey, & Weissling, in press); with amyotrophic lateral sclerosis (e.g., Ball, Beukelman, & Bardach, 2007; Beukelman, Fager, & Nordness, 2011; Fried-Oken et al., 2006); and with motor speech disorders that require multimodal supplementation (e.g., Hanson, Beukelman, & Yorkston, 2013).

Challenges to Participation in Home, School, Work, Healthcare, and Community Environments

The gains that have been made in enhancing the communication of children and adults with complex communication needs through AAC are remarkable and of fundamental importance. But are they enough? The data on long-term outcomes for individuals with complex communication needs suggest otherwise. Despite the important gains observed in specific communication skills, or in specific communication contexts, many children and adults with complex communication needs continue to experience substantial challenges in education, employment, health care, family life, and community living. For example:

- Many children with complex communication needs are still denied the opportunity to participate in appropriate general education due, at least in part, to their limited communication skills. For example, in the United States, more than 55% of children with intellectual and developmental disabilities and over 70% of children with multiple disabilities receive most of their instruction outside regular education classrooms, away from their peers (National Center for Education Statistics, 2013).

- Up to 90% of students with complex communication needs enter adulthood without acquiring functional literacy skills (Foley & Wolter, 2010), undermining their educational achievement, their employment options, their social networks, and their access to independent living.

- Less than 5% of individuals with complex communication needs are employed even part-time due, at least in part, to a lack of effective and efficient communication and lack of functional literacy skills (e.g., McNaughton & Bryen, 2002; 2007; McNaughton, Light, & Arnold, 2003; McNaughton, Light, & Groszyk, 2001).

- A total of 45% of adults with complex communication needs report that they have been victims of crime or abuse; 71% of these individuals have been victimized multiple times and 97% knew the perpetrators (Bryen, Carey, & Frantz, 2003). The majority had no effective way to communicate about these experiences or report the crime/abuse (Collier, McGhie-Richmond, Odette, & Pyne, 2006).

- The overwhelming majority of individuals with complex communication needs who are patients in hospitals have no access to appropriate AAC and struggle to communicate medical needs or provide medical information (Blackstone, Beukelman, & Yorkston, 2015); a recent meta-synthesis concludes that they are at substantial risk for poor health outcomes as a result (Hemsley & Balandin, 2014).

- Between 40% and 60% of people with aphasia experience chronic language impairments that constrain them from participating fully in daily interactions (Beukelman et al., in press).

A large percentage of adults with complex communication needs do not have consistent access to appropriate AAC devices and, as a result, have limited means to participate in their daily lives within their communities. Stancliffe et al. (2010) reported that 91% of adults with severe intellectual and developmental disabilities do not have access to AAC and have no means to participate within activities of daily living; 77% of individuals with multiple disabilities do not engage in any type of community activity, largely due to communication difficulties (Wagner et al., 2005).

Given the increase in knowledge over the past 30 years, why do persons with complex communication needs (and their communication partners) continue to struggle to achieve successful interaction and the

pursuit of valued outcomes (Johnson, Douglas, Bigby, & Iacono, 2009; Mirenda, 2014)? Essentially the challenge is two-fold: There is a need to re-think both AAC intervention and research in order to transform these outcomes. Ultimately, the goals of AAC intervention must be that children and adults with complex communication needs have the opportunity to live happy and fulfilled lives where they are able to participate fully in education, employment, family, and community life; where they are safe and secure, and have access to needed services; where they are respected and valued for who they are; where they have the chance to develop friendships and intimate relationships; and where they have the opportunity to make meaningful contributions to society (McNaughton & Kennedy, 2010; Trembath, Balandin, Stancliffe, & Togher; 2010). Meeting these goals will require changes in AAC service delivery and in intervention research: Both must embrace the challenge of supporting persons with complex communication needs and their communication partners in pursuing valued real world outcomes.

Designing AAC Research and Intervention to Improve Outcomes

The goals articulated by the parent for her preschooler suggest several principles to guide a more holistic approach to AAC intervention and research to improve outcomes for individuals with complex communication needs. These include the need (a) to build on the individual's strengths and focus on the integration of skills to maximize communication, (b) to focus on the individual's participation in real-world contexts, (c) to address psychosocial factors as well as skills, and (d) to attend to extrinsic environmental factors as well as intrinsic factors related to the individual who requires AAC. The International Classification of Functioning, Disability and Health (ICF) (World Health Organization [WHO], 2013) provides a framework that may be helpful for considering each of these principles and their implications for research and practice. This framework has been applied in the AAC field to guide research, service delivery, and policy development (e.g., Fried-Oken & Granlund, 2012; Simeonsson, Björck-Åkesson, & Lollar, 2012).

The ICF model lies in contrast to either a traditional medical model of disability or an exclusively social model of disability (WHO, 2013). The traditional medical model defines disability as a problem intrinsic to the individual; intervention focuses on treatment or intervention with the individual to correct the problem (Beukelman et al., in press; WHO, 2013). Examples of such interventions with individuals with complex communication needs range from traditional restoration therapy with people who have severe chronic aphasia (e.g., Simmons-Mackie, King, & Beukelman, 2013) to intensive verbal behavior therapy for children with autism spectrum disorders who have minimal or no speech (e.g., Howlin, Magiati, Charman, & MacLean,

2009). Although such treatment may effect some positive changes, many bodily structures or functions cannot be fully restored (especially when individuals, such as those with complex communication needs, experience severe impairments). As a result, the treatments often fall short of functional outcomes.

In contrast, the social model of disability sees disability as an extrinsic phenomenon, a problem created by society's reaction to difference; intervention focuses on socio-political change (Law & Dunn, 1994; Simplican, Leader, Kosciulek, & Leahy, 2015). Although numerous authors have highlighted the importance of considering environmental barriers that limit the communication of individuals with complex communication needs (e.g., Beukelman & Mirenda, 2013; Light & McNaughton, 2014), simply working to eliminate opportunity barriers is seldom sufficient to ensure that children and adults achieve meaningful communication and full participation in society.

The ICF framework attempts to integrate these two positions, arguing that:

> Disability is a complex phenomenon that is both a problem at the level of a person's body, and a complex and primarily social phenomenon. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. (WHO, 2013)

Thus, as the ICF model suggests, intervention should consider both intrinsic factors related to the individual with complex communication needs and extrinsic factors related to the environment.

The Individual Who Requires AAC

It is abundantly clear that the AAC field has embraced the importance of the individual with complex communication needs as the central focus of intervention. Traditionally AAC research and practice has focused on small measurable goals for these individuals. Such an approach is consistent with traditional educational planning and reporting, and with the research methods typically used in intervention studies. When viewed within the ICF framework, these skills are typically at the level of body functions or specific activities (e.g., learning to locate specific AAC symbols for core vocabulary within speech-generating devices; learning the hand shapes, positions, movements, and orientations of specific signs; learning to exchange a picture to request an item at snack time; learning to fulfill communicative turns within a book-reading context; learning to use residual speech and visual scene displays to communicate about personal experiences with an unfamiliar partner); these skills are often targeted within restricted settings. There is no question that methodologically sound studies that focus on the acquisition of specific skills are critically important, for they provide evidence-based guidelines

for intervention to build new skills; however, the focus on isolated skills alone is not enough.

Focus on the Integration of Skills to Maximize Communication

Although specific skills are important to build the foundation for communication, Light and colleagues have argued that they are by no means sufficient to attain communicative competence (Light, 1989; Light, 2003; Light & McNaughton, 2014). Rather, communicative competence rests on the dynamic integration of linguistic, operational, social, and strategic skills in response to the communicative demands within real world interactions with various partners in the natural environment.

To date, only a few studies have looked beyond the acquisition of specific skills in isolation to consider their integration in response to the communication demands of the natural environment in order to attain communicative competence. Future research is required to investigate further the effects of interventions, especially those that focus on the acquisition and subsequent integration of more complex skills across domains in order to support the attainment of communicative competence in response to the varied demands of a wide range of communication situations.

Focus on Participation in Real-world Contexts

In order to attain communicative competence, individuals who require AAC must develop sufficient skills to meet the functional communicative demands within real-world interactions with various partners in their natural environment. Communication is not an end goal in and of itself; rather, it is a tool to allow individuals to participate effectively and attain their goals at home, at school, at work, or in the community. Communication is the means by which children learn at school and teachers evaluate this learning; it is the means by which adults fulfill job requirements and impart knowledge to others or learn from others in the workplace; it is the means by which children and adults express needs and wants and ensure that daily living needs are addressed; and it is the means by which children and adults connect with family and friends, building new relationships and maintaining old ones.

If it is recognized that communication is a tool that allows individuals to participate effectively in society and attain their educational, vocational, health, social, and personal goals, then by necessity AAC interventions must also focus on participation within the natural environment (e.g., home, school, work, community) to achieve the desired end results. Yet, AAC interventions with children seldom actually target real-life circumstances within families (Granlund, Björck-Åkesson, Wilder, & Ylvén, 2008), and there is only limited knowledge of how to support the participation of adults with acquired neurological disorders in their daily lives (Fried-Oken, Beukelman & Hux, 2012; Larsson, & Thorén-Jönsson, 2007).

Many of the current models of service delivery pose significant challenges to the delivery of AAC intervention within the natural environments of individuals with complex communication needs; individuals who require AAC may be seen within hospitals, rehabilitation centers, or clinics, away from their natural daily environments and without many of their key communication partners. These models rest on the assumption that skills targeted within these venues will automatically translate to real-world use. Yet, Schlosser and colleagues argued against this "hope-and-wish strategy," emphasizing that AAC interventions must include effective plans to ensure that the recommended goals are valued by the individual, family, and community (Schlosser, 1999) and that the targeted skills are, in fact, generalized to real-world use (Schlosser & Lee, 2000).

Unfortunately, there is limited research to guide intervention to maximize the participation of individuals with complex communication needs in real-world contexts. Of the intervention studies published in *Augmentative and Alternative Communication* over the past 10 years, only 42% focused on interventions within the natural environments of the individuals with complex communication needs and these studies typically addressed a narrow range of situations. In their review of 20 years of communication intervention research with individuals with severe intellectual and developmental disabilities, Snell et al. (2010) reported that, in approximately 40% of the studies, intervention was delivered in decontextualized settings, removed from the natural environment; and in more than 50% of the studies, the intervention was delivered by a researcher, not a natural communication partner. To paraphrase Bronfenbrenner (1979), too often research and intervention focuses on the communication of individuals with complex communication needs when they are interacting with strange partners (e.g., clinicians or researchers) in strange situations (e.g., isolated clinic rooms or research labs) for brief periods of time. As Green (2008) suggested, "… if we want more evidence-based practice, we need more practice-based evidence" (p. i23).

Although the majority of AAC research has focused on the acquisition of specific skills within restricted settings, there have been a small number of exploratory projects that were designed to support the participation of individuals with complex communication needs in the broader social community. For example, Collier, McGhie-Richmond, and Self (2010) described the use of trained communication assistants to support the communication of persons with complex communication needs in a wide variety of community settings, including stores, doctor's offices, educational classrooms, and government offices. The participants reported that they were able to communicate more effectively and had increased control over their lives, especially in the areas of health, legal, and social services. Additional research is needed to advance knowledge and improve practice in supporting the full participation of individuals who require AAC across a wide range of real-world contexts

– home, school, work, healthcare, and community. This new generation of research requires greater methodological rigor, with specific attention to the challenges associated with scaling up intervention and attaining sustained change (Coburn, 2003).

Focus on Long-term Outcomes

Ultimately, developing the communicative competence required to participate effectively in society is a complex process that requires significant learning over time. To date, most of our AAC research has focused on the short-term effects of intervention with minimal consideration of long-term outcomes. Of the intervention studies published in *Augmentative and Alternative Communication* over the past 10 years, most have focused on the evaluation of the effects of very short interventions; in fact, in more than 60% of the studies, the length of the intervention was less than 6 weeks. As a result, it is not yet clear how to best stage AAC interventions over time to maximize outcomes for children and adults with complex communication needs. Many individuals who require AAC experience significant discontinuity in the services that they receive over the long term, with frequent changes in service providers and AAC systems (Smith-Lewis, 1994) that may negatively impact long-term outcomes.

Despite the predominant focus on short-term outcomes in the AAC research to date, there have been some notable exceptions to this trend, including important efforts to define the staging of AAC interventions over time to maximize communication outcomes with various populations of adults with acquired neurogenic disorders (e.g., Yorkston & Beukelman, 1999; Fried-Oken et al., 2012). There has also been some investigation of the outcomes of AAC interventions over time with individuals with developmental disabilities. For example, Romski and Sevcik (1996) conducted a prospective longitudinal study that documented the positive effects of AAC intervention (including the introduction of speech-generating devices and augmented language input) on the communication skills of children with severe intellectual disabilities. Hunt-Berg (2005) reported on a retrospective study of intervention and the resulting outcomes for 16 students who had attended an intensive AAC educational program. She noted the changes in student goals over time, first focusing primarily on issues related to communicative competence, and later, adding goals related to academics and self-determination as students demonstrated increasing competence in the use of their AAC systems. Hamm and Mirenda (2006) examined long-term outcomes for eight participants with developmental disabilities and found that those with greater communicative competence also reported higher quality of life outcomes. Lund and Light (2006; 2007a, 2007b) also reported retrospectively on the long-term outcomes of AAC intervention – this time with a cohort of participants with severe physical and speech impairments who

had received AAC intervention over a 15-year period. They documented outcomes across various levels of the ICF model, including body functions, activities, and participation (e.g., receptive language, reading comprehension, communicative interaction, educational and vocational achievement, self-determination, quality of life). They noted that those who had better participation outcomes also tended to have better body function outcomes and more supportive environments. These retrospective studies lack experimental control; however, they do suggest numerous factors that may affect long-term outcomes for individuals with complex communication needs, including intrinsic factors related to the individuals who use AAC as well as extrinsic factors related to AAC systems, instruction, partners, and environments. Methodologically sound research is required to better understand the progressions of language and communication development, recovery, or loss for individuals who would benefit from AAC, and to determine the most effective staging of AAC interventions over time with individuals with a range of disabilities in order to accommodate changing needs and skills and maximize long-term outcomes.

Focus on the Full Breadth of Communication Goals

With the focus on attaining communicative competence to support the achievement of educational, vocational, social, and personal goals, it is apparent that AAC interventions must focus on the full breadth of communication goals – not just the expression of needs and wants, but also information exchange and social closeness (Light, 1988). Although the effective expression of needs and wants is important for activities of daily living, it is by no means sufficient to attain educational, vocational, social, and personal goals; rather, AAC intervention must focus on supporting individuals with complex communication needs in developing the skills required to exchange information effectively and efficiently and to build positive social relationships with others (Light, 1997). Too often, however, interventions focus on teaching requests for favorite foods or activities to the neglect of teaching skills to promote social interaction and information exchange. For example, in their review of 20 years of communication intervention studies with individuals with severe intellectual and developmental disabilities, Snell et al. (2010) reported that more than half of the studies targeted the communicative function of behavior regulation (e.g., requesting, rejecting). Similarly, of the intervention studies published in *Augmentative and Alternative Communication* over the past 10 years, approximately half targeted simple requests for objects or activities.

It is not surprising that individuals with complex communication needs may demonstrate difficulties with the exchange of information and the development of social relationships if they are not taught these skills. AAC interventions must be well rounded, with a focus on the full breadth of communication purposes

(e.g., expression of needs and wants, social closeness, information exchange, social etiquette), and future research must investigate the effects of such well-rounded interventions on the communication outcomes of individuals with complex communication needs across their natural environments. For example, Trottier, Kamp, and Mirenda (2011) reported the positive impact of a peer-mediated intervention to teach two students with autism to use their AAC systems to support social interactions with peers in their general education classroom. The results provided evidence that the peers were able to support AAC system use by the students with autism, and there was an increase in the participation of these students during the social activities. Future research is required to determine evidence-based interventions to promote social closeness and effective information exchange as well as the expression of needs and wants.

Focus on the Strengths of Individuals with Complex Communication Needs

It is interesting to note that most AAC research and practice tends to focus on deficits experienced by the individual with complex communication needs, with much less attention to their strengths and capabilities. Ironically, the persistent focus on deficits alone may cloud recognition of the unique characteristics of the individual and important strengths that may be leveraged to maximize outcomes. In his book, *Beautiful eyes: A father transformed*, Paul Austin writes about his experiences with his daughter, Sarah; he highlights how he was consumed for many years by the fact that she had Down syndrome and as a result failed to see her as a person with a rich array of strengths: "Over time…Sarah became less and less 'my daughter with Down syndrome' and more and more 'my daughter.' No qualifiers needed." (Austin, 2014, p. 272).

Unfortunately, much of the research to date with individuals with complex communication needs reflects this deficit model. Numerous studies have compared the performance of children or adults with complex communication needs to that of individuals without disabilities. In most of these studies, individuals with complex communication are found to be "wanting;" they are outperformed by individuals without disabilities. But what does this research contribute to improving outcomes for individuals with complex communication needs? Perhaps these studies reflect a Type III error – asking the wrong question (Mawn & Goldberg, 2012). Might it be more informative to investigate the strengths that individuals with complex communication needs bring to their daily interactions and consider ways to capitalize on these strengths to maximize outcomes? Adjusting the lens of our research and practice to focus on strengths, not just deficits, may lead to important advances. Smith (in press) illustrates this point when she contrasts the conclusions drawn about the language and communication development of children who use aided AAC when viewed from a linguistics perspective compared

to that of conversational analysis: When viewed from a linguistics perspective, conclusions focus on the children's limitations in terms of their pragmatic, semantic, and morphosyntactic contributions compared to typical development; however, when re-framed and viewed from the lens of conversational analysis, the children's contributions are viewed as "… conversational moves that occur as part of a shared communication problem-space, where collaboration is essential if meaning is to be progressed" (Smith, in press).

To date, there has been only minimal attention in the AAC field to identifying the strengths of individuals with complex communication needs and building on these strengths to maximize outcomes. Although limited, there has been some important work that has focused on the strategic competence of individuals who have complex communication needs, that is, on their use of strategies to bypass limitations in their linguistic, operational, and social skills to attain successful communication. For example, more than 30 years ago, Holland (1982) documented the successful strategies used by people with aphasia to maximize their communication in the face of significant linguistic impairments.

More recently, Mirenda and Bopp (2003) synthesized a wide range of strategies that have been used by individuals with complex communication needs to successfully overcome not just linguistic constraints, but also operational and social limitations in order to enhance communication. Ironically, in developing the compendium of strategies, Mirenda and Bopp drew largely on the writings of individuals with complex communication needs who themselves chronicled their successful strategies; they found only a few studies that investigated the strengths and strategic competencies of individuals with complex communication needs. Clearly the AAC field has much to learn from individuals with complex communication needs who have capitalized on their strengths to bypass deficits and overcome environmental barriers to their communication. As Mirenda and Bopp (2003) concluded:

> Sometimes strategies are required to overcome the fears or misconceptions of unfamiliar listeners, to regain conversational control, to adjust interaction styles in different environments, or to maintain privacy. Other strategies may be required to overcome linguistic constraints … or to deal with operational constraints … Whatever the situation, the solutions should always reflect the diversity and uniqueness of the individuals who use AAC ... It is only through the development of strategic competence that individuals who use AAC will be truly able to … achieve a level of communicative competence that is equal to that of their naturally speaking peers. (pp. 433–434)

Focus on Personal Psychosocial Factors

As noted earlier, AAC research and practice has focused primarily on teaching specific linguistic, operational, and social skills. Although these skills are necessary, they may

not be sufficient to attain meaningful outcomes, given that individuals with complex communication needs face numerous constraints and challenges as they strive to communicate. The ICF model emphasizes that an individual's overall health and functioning is influenced by his or her body function and systems, activities, and participation, but that these are in turn modulated by personal factors that include, for example, gender, age, coping styles, social background, education, profession, past and current experience, overall behavior pattern, character, and other factors that influence how disability is experienced by the individual.

In discussing her goals for her daughter, the parent (quoted at the beginning of this paper) hints at the importance of personal psychosocial factors such as motivation, attitude, confidence, and resilience in determining outcomes. Light (2003) and Light and McNaughton (2014) also highlighted the importance of personal psychosocial factors in their proposed model of communicative competence, emphasizing that communicative competence rests not just on the integration of linguistic, operational, social, and strategic skills, but also on a range of psychosocial variables. Specifically, they underscored the importance of the following factors: (a) motivation that defines the individual's drive to communicate with others, (b) attitude that influences the individual's willingness to use AAC, (c) confidence that impacts the propensity to actually act (i.e., to try to communicate), and (d) resilience that defines the individual's persistence in the face of barriers, adversities, and communication failures (Light, 2003; Light & McNaughton, 2014). These factors are of critical importance, for they define the resources that the individual may bring to bear on the communication process. For any individual with complex communication needs, psychosocial factors may vary across partners and across communication contexts.

Psychosocial factors are important for all individuals, but perhaps especially so for those who are first learning to use AAC. In his book, *Schuyler's Monster*, Rummel-Hudson (2008) described his family's search for an effective AAC intervention for his daughter, Schuyler. Dinosaurs were a favorite topic for Schuyler, and Rummel-Hudson described the impact on his daughter's motivation and attitude when he added the sound of a dinosaur's roar (i.e., "*rire*") to her recently acquired AAC device:

> …Schuyler lost her little mind with joy. Soon she was using it to accentuate all the other little phrases she'd been figuring out at an astonishing rate all over the past few days.
> "*I want ice cream. Rire!*"
> "*I want drink milk. Rire!*"
> "*I feel happy. Rire!*"
>
> …Every statement closed with a monster roar, at the sound of which we'd feign terror. Every time the box said, "*Rire!*" she would burst into laughter. We had a great deal of fun and she was completely fired up about the device. All positives in my mind. (p. 224)

Despite the importance of psychosocial factors in determining outcomes, to date, there has been limited attention to these factors in AAC research and practice. Of the intervention studies published in *Augmentative and Alternative Communication* over the past 10 years, only a very small percentage focused on psychosocial factors such as motivation, attitude, confidence and resilience.

There are, however, some notable exceptions to this trend. In some of the earliest work on psychosocial variables in the AAC field, Lasker and Bedrosian (2000) argued that attitudes toward AAC predisposed the use of AAC (or lack thereof) by individuals with acquired disorders. They proposed a model of AAC acceptance that considered the impact of three sets of factors: (a) milieu factors (e.g., partners, setting, time of day), (b) person factors (e.g., disability, personality, age, skills, needs, history, expectations), and (c) AAC-related factors (e.g., ease of learning, appearance, functionality). More recently, a new line of research has emerged to investigate the preferences of individuals with developmental disabilities for AAC systems (see van der Meer, Sigafoos, O'Reilly, & Lancioni, 2011, for a systematic review). Like the earlier work by Lasker and Bedrosian, this line of research is built on the premise that individuals with complex communication needs may be more apt to learn and use AAC systems when they are able to exert some level of self-determination. Beyond the latter work that is focused on the attitudes and preferences of individuals with complex communication needs, there have also been several studies focusing on intervention to build the problem-solving skills of individuals who use AAC (e.g., Light et al., 2007; McCarthy, Light, & McNaughton, 2007). Of particular note is the study by Light and colleagues which provided instruction in problem-solving skills for adults who used AAC, who in turn mentored adolescents and young adults who required AAC, with a view to building the confidence and resilience of these younger protégés to enhance their outcomes.

Despite these initial ventures to explore psychosocial and other personal factors that may contribute to positive outcomes, there remain a myriad of unanswered questions. Future research is urgently required to advance understanding of these psychosocial factors as well as other personal factors and to determine ways to cultivate the motivation, positive attitude, confidence and resilience of individuals with complex communication needs in order to promote successful outcomes.

Environmental Factors

Despite the significant importance of the individual's skills and other personal factors, it is not sufficient to simply focus on these intrinsic factors. Rather, as noted earlier, the ICF model asserts that disability is a complex social phenomenon that involves the interaction between the intrinsic characteristics of the individual and the extrinsic factors associated with the

social context in which the person lives (WHO, 2013). In order to understand human development, health and function, the entire ecological system needs to be taken into account, including not only the individual but also successive levels of the social system, ranging from the immediate dyadic interactions between the individual and partners (e.g., the individual's interactions with family members, friends, teachers at school, or colleagues at work) to the connections between these (e.g., the connection between the child's teacher and his parents, between service providers and family) to the larger social system that impacts the individual (e.g., workplaces, transportation, school districts, neighborhoods) and finally to the broad cultural values, politics, customs, and laws of society (Bronfenbrenner, 1979).

In the AAC field specifically, the participation model, described by Beukelman and Mirenda (2013), captures many key aspects of this type of socioecological model with an emphasis on not only the intrinsic characteristics of the individual with complex communication needs but also the environmental supports and the opportunity barriers inherent within the social system. Specifically, the participation model details a range of opportunity barriers that might limit communication for individuals who require AAC, including policy, practice, or attitude barriers at the societal level; as well as knowledge and skill barriers at the more immediate level of dyadic interactions in the family, at school, in the work environment, or in the community (Beukelman & Mirenda, 2013).

Although in theory, the participation model has garnered substantial acceptance in the AAC field, to date, there is only limited evidence of its effective implementation. Too often AAC intervention seems to focus primarily on the individual with complex communication needs with only minimal attention to partner instruction and even less attention to societal change. The research in the AAC field reflects this imbalance. Of the intervention studies published in *Augmentative and Alternative Communication* in the past ten years, only a third of the studies provided intervention to teach partners (e.g., parents, paraprofessionals) skills to facilitate their interactions with individuals with complex communication needs; and only a tiny percentage investigated the effects of interventions to eliminate policy, practice, and attitudinal barriers within society.

The lack of attention to communication partners in AAC intervention is especially concerning, given the convincing evidence establishing the efficiency of partner instruction and its positive impact on the communication of individuals with complex communication needs. A recent meta-analysis by Kent-Walsh, Murza, Malani, and Binger (in press) concluded that communication partner instruction was highly effective and efficient: Partners learned to modify their interaction strategies successfully in a short amount of time; and these changes had positive effects on the communication of individuals who used AAC. Partner instruction is clearly warranted, given the amount of time that

parents, other family members, educators, and vocational personnel spend with individuals with complex communication needs, and their role in determining opportunities and supports for communication (or the lack thereof). To date, the majority of the research has focused on the effects of instruction of educators and parents of children who require AAC within a limited range of contexts such as book reading (Kent-Walsh et al., in press). Future research is required to establish evidence-based practices for the instruction of a wide range of partners of individuals who require AAC, across the life span, within diverse contexts; research is also required to investigate effective and sustainable approaches to integrate partner instruction into models of AAC service delivery.

Beyond partner instruction to enhance immediate dyadic interactions, the ICF framework and the participation model both also highlight the importance of intervention to effect broader societal change. In his book, *Far from the Tree*, Solomon (2012) discussed society's reaction to disability and other human differences:

> Difference and disability seem to invite people to step back and judge. Parents judge what lives are worth living, and worth their living with; activists judge them for doing so; legal scholars judge who should make such judgments; doctors judge which lives to save; politicians judge how much accommodation people with special needs deserve; insurance companies judge how much lives are worth. (pp. 43–44)

All of these judgments have significant impacts on the quality of life for individuals with complex communication needs.

Intervention is required to eliminate attitude, practice, and policy barriers that limit the participation of individuals who use AAC. There have been numerous studies that describe social attitudes towards individuals with complex communication needs (see McCarthy & Light, 2005, for a review), but to date there have been only a small number of studies (e.g., Lilienfeld & Alant, 2005; McCarthy, Donofrio-Horwitz, & Smucker, 2010) that have investigated techniques to promote positive attitudes and maximize social acceptance of individuals with complex communication needs.

A number of qualitative studies have described the impact of systemic barriers and supports on outcomes for individuals with complex communication needs, including, for example, (a) children within the educational system (e.g., Birmingham & Light, 2014; De Bortoli, Arthur-Kelly, Foreman, Balandin, & Mathisen, 2011; Finke, McNaughton & Drager, 2009; Kent Walsh & Light, 2003), (b) adults with complex communication needs who are employed (e.g., McNaughton et al., 2001; 2002), (c) adults engaged in leisure activities within the community (e.g., Dattilo et al., 2008), and (d) individuals with complex communication needs within the health care system (Hemsley & Balandin, 2014).

While the need is clear, only a very small number of studies have investigated techniques to effect social change in education, employment, community, and/or health care environments to enhance outcomes for individuals with complex communication needs. For example, Collier et al. (2006) provided a preliminary investigation of a 3-year intervention program designed to reduce the risk of sexual abuse of adults who required AAC; they documented the positive impact of a broad range of services (e.g., education about sexuality, rights, and abuse; access to appropriate communication tools; access to community legal services). Future studies, utilizing strong research methodologies, are required to document the important advocacy efforts already underway in the AAC field; to evaluate the effectiveness of initiatives to dismantle policy, practice, and attitude barriers; and to develop replicable and sustainable interventions to address system change in key areas (e.g., advocacy efforts to ensure funding of assistive technologies, access to appropriate education, workplace accommodations, etc.). Future research is urgently required to effect positive social change to improve the quality of life of individuals with complex communication needs, not just at the dyadic level with family members or educational/vocational personnel but also within much broader societal contexts.

Conclusions

The AAC field has come a long way over the past 30 years: Research has clearly established the benefits of AAC, and evidence-based AAC interventions have significantly enhanced the communication of many children and adults with complex communication needs. However, the work is by no means complete. Now, the challenge is to continue to build on the foundation of existing AAC research and services, and to extend this work and embrace a more holistic view in order to maximize outcomes for individuals with complex communication needs. Specifically, there is an urgent need to extend AAC research and intervention (a) to build on the individual's strengths and focus on the integration of skills to maximize communication, (b) to focus on the individual's participation in real-world contexts (e.g., family, school, work, healthcare, and community contexts), (c) to address psychosocial factors (e.g., motivation, attitude, confidence, resilience) to maximize the resources that the individual brings to bear on the communication process, and (d) to focus on environmental factors to eliminate opportunity barriers and maximize social supports for the individual with complex communication needs. This work will require greater collaboration among clinicians, researchers, individuals who use AAC, and their families to implement state-of-the-art research methods to investigate the impact of innovative AAC services on short-term and long-term outcomes in the real world. With improved AAC research and evidence-based interventions, children and adults with complex communication needs will have the opportunity to live happy and fulfilled lives where they are able to participate fully in education, employment, health care, family, and community life; where they are safe and secure; where they are respected and valued for who they are; and where they have the opportunity to make meaningful contributions to society.

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